Calling *All* Voices

Stories from Black Community Members on Learning to Live Well with Dementia

> **"We are lacking in terms of getting the knowledge about this disease. We have to dig a little deeper on almost everything that we do to try to get the answers that we want. It's just not handed to us. We don't have access, and if we do, we have to go further to get it."**
>
> *– Chris Tann, living with dementia*

GCAD
Global Council on Alzheimer's Disease™

Dementia Action Alliance

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Introduction

In 2021, the Global Council on Alzheimer's Disease (GCAD) and Dementia Action Alliance (DAA) co-authored a first-of-its-kind paper, Hear Our Voices. This paper shared insights from a series of interviews of people living with dementia and their care partners, and it revealed how – along the dementia journey – people often have experiences that do not align to their expectations. This paper sought to fill a gap in the literature by offering first-person, authentic testimony about experiences with agitation due to dementia.

The project prompted a broader recognition: we need to hear more voices – voices that speak to living with dementia from diverse perspectives, and we need to amplify those voices from communities that are marginalized, underserved, and unheard. ***Calling All Voices: Stories from Black Community Members on Learning to Live Well with Dementia*** amplifies some of these voices.

In the pages that follow, we share the perspectives and experiences communicated to us through extensive conversations with Black Americans living with dementia and their care partners. These individuals bring to this paper a rich diversity of backgrounds, geographies, and types of dementia.

They share the challenges they faced and the lessons they learned in order to live well with dementia. Some of these challenges are very familiar across the dementia community; others less so, such as the experiences of bias and discrimination in the healthcare system, the stigma and silence around the condition, and the shortage of culturally appropriate support and resources.

We would fail in our goal to hear the whole story, however, if we only shared challenges. Throughout our conversations, we heard stories of hope, creativity, and tenacity. We heard stories of perseverance and triumph. And we heard invitations to join the advocacy efforts to support the Black community affected by dementia.

We would like to thank the courageous people who shared their experiences with us. Their insights and stories are the only reason this paper came to be. Yet we also recognize their experiences do not – and must not – be presented as representing all experiences across the Black community living with dementia. We rather hope this paper is a step in a much larger journey.

From the outset, we would like to recognize a limitation of this paper. Our conversations were with Black Americans. Many of the conclusions and insights that follow will have limited global application. As part of our ongoing work, we will strive to gain broader perspective to understand the experiences outside the U.S. – not only for Black people, but for people of all races and ethnicities living with dementia.

We would therefore like to use this paper to ***call all voices*** of the Black community living with dementia to share their stories. Whether it's with GCAD, DAA, a support group, another person living with dementia, or anyone else, each voice helps to create a better, more equitable future for people living with dementia.

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Acknowledgments


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Valene Campbell


Harold Craig


Saundra Craig


Gretchen Carter Lowery

This project is in collaboration between the Dementia Action Alliance (DAA) and the Global Council on Alzheimer's Disease (GCAD). We would like to thank everyone who graciously shared a story with us and allowed us to share it with you. This project would not have been possible without their courageous voices.

We would also like to extend our deep gratitude to Debra Tann, a care partner whose husband is living with dementia, for her expert voice and the skill and compassion with which she led the conversations that became this paper.

Brian Van Buren,
living with dementia

Valene Campbell,
care partner

Harold Craig,
living with dementia

Saundra Craig,
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Gretchen Carter Lowery,
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James Lowery,
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Terrie Montgomery,
living with dementia

Chris Tann,
living with dementia

Debra Tann,
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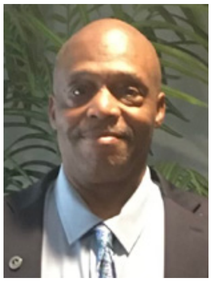
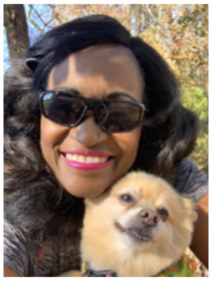
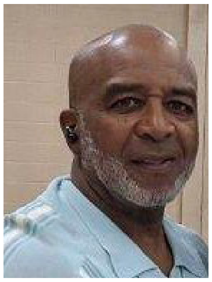
Will Smith,
care partner


James Lowery


Terrie Montgomery


Chris Tann


Debra Tann


Will Smith

We would like to thank Karen Love, CEO of Dementia Action Alliance and High Lantern Group for their expertise and critical insights in the development of this paper.

Dementia in the Black Community: Barriers and Opportunities

In the U.S., the Black community bears disproportionate health, economic, and societal burdens of dementia. Older Black adults are approximately twice as likely as older White adults to develop dementia, and Black Americans hold around one-third of total societal costs for dementia, despite making up less than 15% of the population. [1, 2, 3]

These disparities have arisen from inequality in life experiences, socioeconomic and environmental well-being, access to healthcare, and other factors linked to dementia risk.[2] It is also more difficult for Black Americans with dementia to receive a timely diagnosis and high-quality care. Evidence suggests that Black older adults are more likely to experience discrimination when seeking care and are more likely to have missed or delayed dementia diagnoses.[1, 4]

Despite these challenges, Black community members have made progress living well with dementia. New clinical trials,[5] advisory councils,[6] conferences,[7] and church-based education efforts[8] are creating more opportunities for Black people affected by dementia. Community members are demonstrating hope, perseverance, and the capacity to respond to systemic barriers.

As community members push for progress, it is apparent that a critical piece of the broader dementia conversation has been unheard: the voices of Black people living with dementia and their families. This paper aims to help fill this gap – putting the spotlight on Black American's experiences, in their own words.

Navigating the Healthcare System – And Its Biases

Black Americans face systemic barriers to finding, accessing, and taking advantage of equitable medical care. Further, due to a history of discrimination, many Black people are hesitant to trust medical professionals and the healthcare system, especially for clinical research and new treatments.

In response, many Black Americans are advocating for themselves, their families, and their communities. They are educating themselves on dementia, insisting on clear, compassionate communications from healthcare providers, and pushing the healthcare system to ensure more equitable care.

Challenges:
Historic and Ongoing Bias in the U.S. Healthcare System

> “A lot of us are holding trauma and memories of racism, things like the Tuskegee study.”
>
> *- Harold Craig,* care partner

A History of Exploitation and Discrimination

The Black community has experienced a long history of discrimination, racism, and exploitation when attempting to access healthcare. Today, many Black older adults and their families are reluctant to seek care and trust healthcare professionals. According to the Alzheimer’s Association, nearly 70% of Black Americans do not want to participate in clinical trials because they don’t want to be “guinea pigs.” [9]

> “Historically speaking, we can look to several instances where research has been unethically placed on our community, and we have been lied to, tricked, and used for very harmful experiments and very harmful research. There’s just so much history, and it’s not even that long ago.”
>
> *- Valene Campbell, care partner*

> “It’s common knowledge that there are disparities in the African American community when it comes to getting medical care. Sometimes people are reluctant to get care because they’re scared of the Tuskegee study.”
>
> *- Terrie Montgomery, living with dementia*

Spotlight on the Tuskegee study

The Tuskegee study weighs heavy on the minds of Black Americans. From the 1930s through the 1970s, the U.S. Public Health Service conducted a study tracking the course of syphilis in Black men and intentionally withheld treatment of penicillin, even once it became the standard of care.[10] The Tuskegee study was mentioned by multiple people interviewed for this paper.

Underrepresentation in Clinical Trials

Black Americans make up less than 2% of participants in Alzheimer's clinical trials and in the last two decades, little progress has been made for better representation.[11, 12] Consequently, new treatments may be less effective for Black people[11], deepening distrust in both the medical and research community. Researchers and health systems must do more to bring equitable representation in clinical trials and dementia research.

> "The problem with clinical trials is that most of the people in them are White. Few are people of color. You can't really get good samples from just White people."
>
> *- Brian Van Buren, living with dementia*

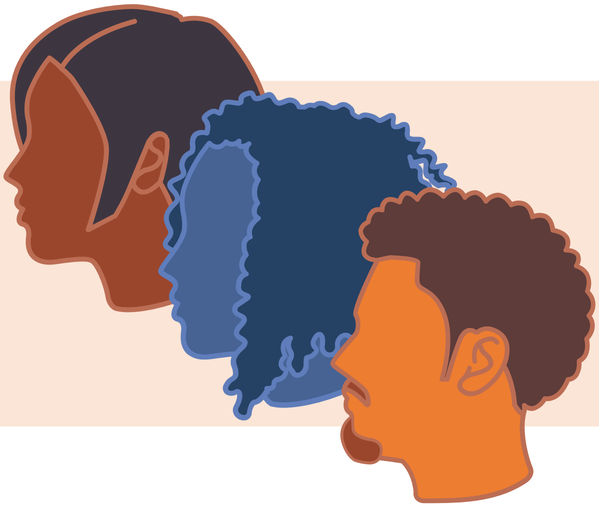
> "We're not involved in the clinical trials. This creates a cyclical issue where we don't know how drugs affect our community, and there's distrust, so we don't get involved in the trials."
>
> *- Valene Campbell, care partner*

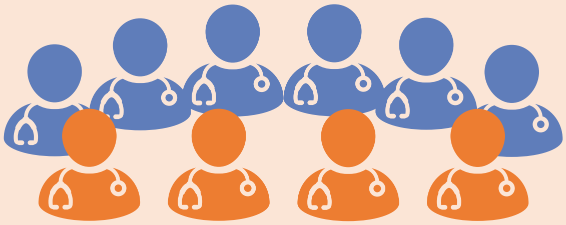
Unequal Access to Care

Black Americans face unequal barriers to care. Families may struggle to pay out-of-pocket costs, and the facilities and specialists that are best suited for a family's needs may be inaccessible. Some families may delay seeking care for symptoms of dementia because they do not see themselves represented in the educational campaigns for dementia or the care teams who treat them.

2 out of 3

of Black Americans believe that receiving excellent dementia care is harder for them,





less than 1/2

believe their providers understand their racial or ethnic background.[13]

"Many in the community can't afford to go to the doctor, or their insurance is not accepted, or they don't know how to get care. For those that do go to the doctor, they may go to one doctor in one neighborhood, but they wish they could go to a different doctor in a different neighborhood that they can't afford."

- *Terrie Montgomery, living with dementia*

"There is the perception that perhaps dementia doesn't happen in certain communities, simply because we don't see our faces represented in the literature. There may be organizations or support systems that are out there, but they are underutilized, because our face is not connected to the diagnoses."

- *Valene Campbell, care partner*

Experience of Medical Bias & Discrimination

Black Americans report bias, misperceptions, and discrimination when they access care for dementia. This includes providers dismissing reported signs and symptoms of dementia, assuming that Black people are less intelligent, or slowing down the diagnostic process.[14] Studies have found Black Americans are consistently undertreated for pain relative to White patients,[15] and a recent report found half of White medical students and residents held one or more false beliefs about supposed biological differences between Black and White patients.[16] Such ongoing medical bias makes it less likely for Black Americans to seek out and receive high quality care.

> “People look at you as being less intelligent. That’s a stigma that is affiliated with dementia, no matter what color you are. But when you add your economics or being female. It can make a difference. Sometimes the healthcare provider is not paying attention to what you’re saying. They dismiss you.”
>
> \- *Terrie Montgomery, living with dementia*

> “Racism is something that seeps into all corners and in all facets of our lives. Oftentimes we are misdiagnosed and under diagnosed.”
>
> \- *Valene Campbell, care partner*

Distrust in the Medical System

Distrust in the medical system is not only shaped by a history of marginalization, it is also influenced and reaffirmed by current experiences of discrimination. Experiences of access inequity, stereotyping, and disrespect from providers all contribute to feelings of distrust in the medical system among the Black community.[17]

“I think people are very hesitant, not only to see the doctor, but to even receive information or go out and try to find information pertaining to their diagnosis.”

- Chris Tann, living with dementia

“The distrust is obvious from my perspective. If you look at COVID, Black people are reluctant to get the shot. That shows you right there that they don’t really trust the doctors. They’re the last to embrace new information, whereas other cultures are quick to utilize it. Our people don’t trust a lot of stuff being put out there by doctors and scientists. They always seem to think that we’re the guinea pigs of a new medication.”

- Gretchen Carter Lowery,
living with dementia

Black Community Members are Advocating for Fair Treatment and Equitable Care

“You have to be your own advocate.”

- *Terrie Montgomery,*
living with dementia

Becoming An Advocate

Black community members say they must serve as their own best advocates for their health and well-being. Advocacy can take many forms: from speaking up to ensure your health care needs are being met, to researching resources, to educating others, and to preparing for interactions with healthcare providers.

“Being African American, and being someone with dementia, I think it’s very important to speak up. I come prepared to talk to the doctor, or to talk to anyone, and to let them know ‘talk to me normally.’”

- Terrie Montgomery, living with dementia

“Advocacy work is highly individualized. And for me it’s always representing myself and my husband. It’s my responsibility to advocate for him and for us. It’s very important that I make sure he gets the absolute best care. I’m accustomed to research, to reading, and to digesting information, so for me, I became an advocate day one... One time our doctor used the word ‘demented.’ I was absolutely appalled, so I used that moment for a teaching opportunity. As an educator, my responsibility is not to chastise, it’s to raise consciousness, to help people process and think critically about the words they are using.”

- Debra Tann, care partner

Advice for the Medical Community

Members of the Black community navigating the healthcare system have advice for healthcare professionals. Here's what they ask medical providers to consider for better, more compassionate dementia care:

"Ask: 'How was your experience today?' 'Could I have done better?' or 'Do you feel comfortable?' 'Did you understand our conversation, or do you have anything that we could clarify?' 'Are you fine with the medications, and are you familiar with the side effects?'"

- *Terrie Montgomery, living with dementia*

"Be concerned about the patient, but also about their care partner. Care partners need more support than doctors often realize. It is rare for a doctor to ask the care partner: 'How are you doing?'"

- *Harold Craig, care partner*

"Put yourself in our shoes, because you don't know unless you experience it. You can read it in pamphlets, and you can read it in books, but you really don't know until you've walked in your brothers' or your sisters' shoes."

- *Gretchen Carter Lowery, living with dementia*

"Give messages of hope like "things will get better even if she will not get better" I think too often the message is "it will get worse; it is uncurable; here are meds", "you are dealing with death", "I feel sorry for you."

- *Will Smith, care partner*

"Representation matters. We need to be able to see ourselves in these treatments, see ourselves in the educator, see ourselves, and know how we are affected."

- *Valene Campbell, care partner*

Black Individuals Are Responding to Stigma and Silence in Their Communities

Stigma and silence around dementia pervade the Black community. According to a recent study, the Black community tends to have negative associations with dementia, correlating it with states of fear and sadness.[18] This stigma, often driven by lack of awareness, can motivate individuals and families to conceal dementia diagnoses. It has been shown, however, that within the Black community, education can break this cycle, change perceptions, and reduce stigma.[18] Many of the individuals interviewed for this paper are doing just that.

Stigma and Silence Around Dementia in the Black Community

> **"My kids thought I was telling too many people about the diagnosis. I think they felt shame about their mother's condition, especially because she was so young. So, they wanted to keep it private."**
>
> ***- Will Smith,***
> **care partner**

Stigmatization of Dementia

Black care partners are twice as likely than care partners of other races to report concerns about dementia stigma.[19] For the Black community, according to the USC Suzanne Dworak-Peck School of Social Work, "seeking mental health care is often viewed as a weakness, running counter to the survivalist mentality born from systemic oppression and chronic racism."[20] Compounded with a lack of understanding of dementia, these attitudes can cause people to view dementia as senile, to fear it, and to cut ties with those who have it.

"In the Black community, dementia is often seen as senile and considered a White disease."

- *James Lowery, care partner*

"Especially within the African community, mental health issues have always had a stigma, whether it be dementia or other things."

- *Brian Van Buren, living with dementia*

"I think people are afraid of dementia, they think it's bad and want to stay away from it like it's contagious. When you don't understand something, you don't want to deal with it, so you just silence it."

- *Will Smith, care partner*

Silence Around Dementia

For many members of the Black community, dementia is shrouded in secrecy. Stigma, lack of education, and cultural attitudes toward mental health and hardship perpetuate the silence.

"It was initially very challenging to speak about the diagnosis, traditionally we come from a community that doesn't speak about hardship, we just endure."

- Valene Campbell, care partner

"There's this unspoken rule in the Black community that what goes on in the house stays in the house, we don't discuss it with other people."

- Brian Van Buren, living with dementia

"I think dementia is something that maybe we as a culture don't like to talk about. I know from reflecting back with my grandparents and other friends' grandparents, they would always make the joke 'oh Uncle Joe, don't pay no attention to him, he's senile.' They would just say 'he is forgetful, he's getting old, he's senile.'"

- Gretchen Carter Lowery,
living with dementia

Building Community and Awareness Around Dementia

> **I recognized that in order for us to educate others, we have to talk about our own situation. Sharing my mother's diagnosis was an opportunity to educate my community."**
>
> ***- Valene Campbell,***
> **care partner**

Raising Awareness Around Dementia

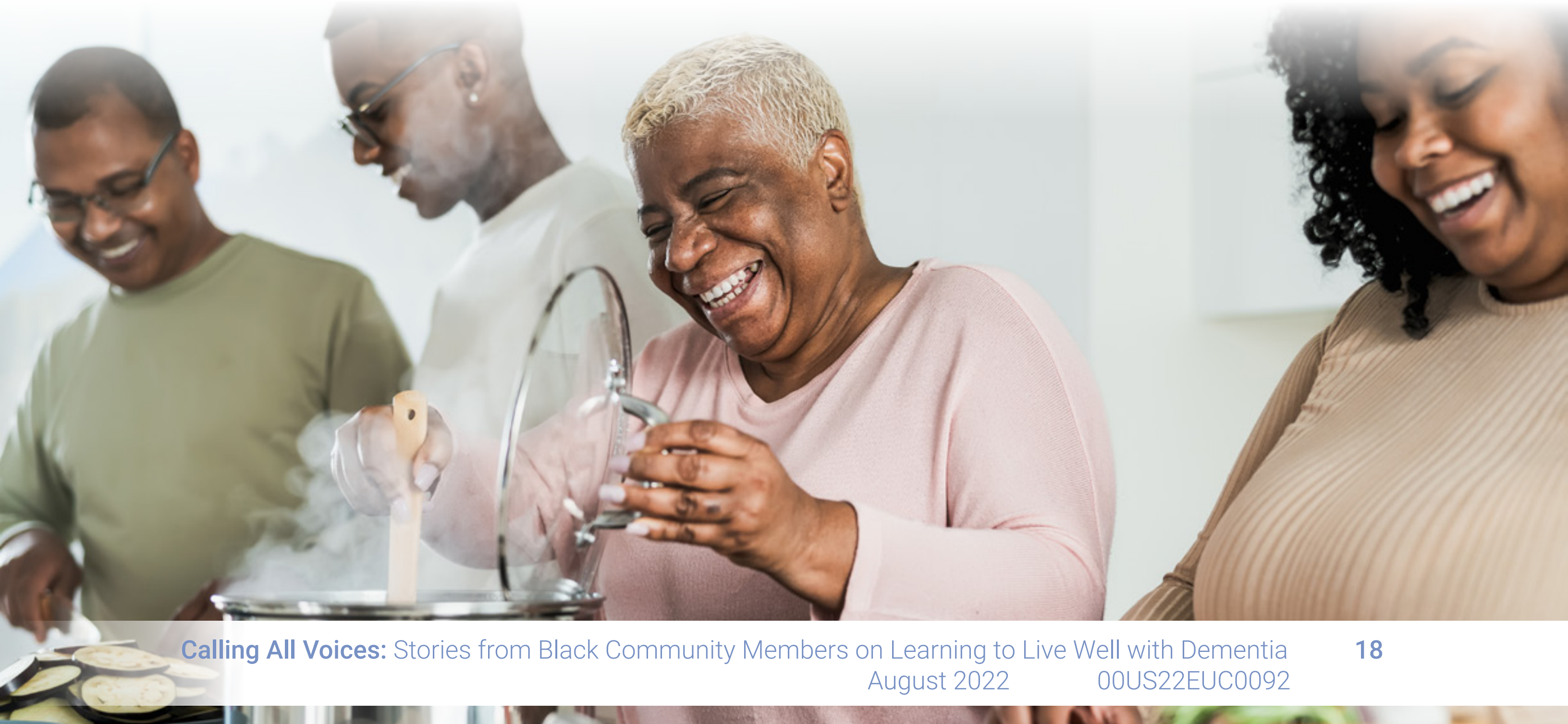
In response to the stigma and silence that often surrounds dementia, people in the Black community are working to raise awareness. They have opened up to others about their, or a loved one's diagnosis, they have encouraged their community to get tested, and they are spearheading education.

" I have a passion and believe in trying to help people - to get them to understand what dementia is all about, especially in our Black community. I'm trying to encourage people to go to the doctor and get tested. They can't count us if we don't tell our story. They can't count us and say how we were treated unfairly."

- Terrie Montgomery, living with dementia

" I've reached out to a couple pastors and gave them some information on dementia."

- Chris Tann, living with dementia



Finding Support and Guidance from the Community

From our interviews, we heard that Black community members are finding and building community through their neighbors, colleagues, and support groups. In fact, nearly half of Black American care partners participate in a support group, compared to 29% of care partners of other ethnicities.[19]

“Our neighbors were aware of my wife’s dementia. They checked in and called me if she wandered away. In the past, the police even asked for my phone number so they could call me if she wandered. I would’ve had her wear a dementia bracelet, but she didn’t need to because the community was so supportive. Everyone worked together to make sure she was safe. That made me feel safe.”

- Will Smith, care partner

“I had a colleague whose husband had dementia. She was very open about her husbands’ condition and gave me a lot of advice. I followed her lead in sharing my wife’s diagnosis.”

- Harold Craig, care partner

“The Alzheimer’s Association initially tried to start a Black support group, but there were White people trying to assist African Americans and that just doesn’t work. So I suggested to them that ‘maybe you should allow the facilitators to be African American.’ As of today, we have many people involved and the support group has really assisted people in finding answers, finding references, and finding medical care.”

- Brian Van Buren, living with dementia

Black Individuals Have Found Ways to Live Well with Dementia

For all people with dementia, it is harder to “live well” with the condition if there is a lack of resources and support. Black Americans living with dementia and their care partners are working to fill the gap. Their work inspires optimism, perseverance, and hope.

Lack of Resources and Tools Can Create Challenges to Living Well with Dementia

> **Just like many other people, I wasn't provided with any resources when we left the doctor's office."**
>
> ***- Debra Tann,***
> **care partner**

At diagnosis, almost 85% of Black care partners report that they wish they had received more information about dementia and treatment options.[19] Of the care partners surveyed, Black care partners were significantly more likely than care partners of other races to wish they had received more information. In our interviews, care partners and individuals living with dementia expressed frustration with the lack of resources and support provided at both diagnosis and during the ongoing management of dementia. In some cases, their doctors did not even provide a pamphlet.

"When my wife was first diagnosed, the doctor did not give us any resources."

- Harold Craig, care partner

"I don't believe there are dementia resources in our rural community, at least not until you need assisted living."

- James Lowery, care partner

“What was so amazing to me is how far behind we are compared to when you are diagnosed with cancer or other conditions. Not only are you provided with information, but the physician sits down with you, and sometimes they even give you a Kleenex because they know they’re going to give you some difficult information. With our dementia diagnosis, we were left on our own to navigate.”

- Debra Tann, care partner

“I really didn’t get much help from the doctors. They would try to push me off to someone else – a social worker or therapist, but even they were not particularly helpful.”

- Will Smith, care partner

“My doctor told me to go home and get my affairs in order, which basically was telling me to go home and die.”

- Brian Van Buren, living with dementia

Strategies for Living Well with Dementia

> **I say to people getting the diagnosis is the best thing that ever happened to me because it gave me a purpose and direction in my life."**
>
> ***- Brian Van Buren,***
> **living with dementia**

Practicing Self-Care

For care partners, it is critical to take time for self-care. Self-care can take an indefinite number of forms, but it may involve finding community, creating routine, carving out alone time, and practicing hobbies or activities that provide meaning. It can help care partners to manage stress, cope with their emotions, and empower them to provide the best support they can.

"I wake up at four or five. I'll read my mom's messages from the Bible, then I'll pray, meditate, go for a walk or run, work out, and then drink tea. This way I've already had a good day before everyone else is up."

- Will Smith, care partner

"I go into my office to have time for myself. This is how I cope as my wife's dementia progresses."

- James Lowery, care partner

"I know how important it is to reach out to the organizations that specialize in supporting caregivers so I'm doing that, though I'll say it took me some time to get there. But I just know it's not something that can be managed by yourself and if those communities are out there, it's good to tap into them. I've noticed these conversations are making me feel a little more comfortable being able to speak and divulge and exchange information."

- Valene Campbell, care partner

Finding Ways to Become and Remain Active

Members of the Black community have demonstrated that it is possible not only to remain active with dementia but also to take on new activities and discover newfound meaning in life. These activities can take any form, but all provide opportunities for engagement, learning, and direction.

“Right when they tell you that diagnosis, find out what group you want to look up. Once you get involved, share some of your talents and stop thinking about your diagnosis. Think instead about the things that you are still able to do, whether it is teaching music, dancing, whatever you can do, share it.”

- Terrie Montgomery, living with dementia

“I’ve always been active in the community and active in our church. I enjoy teaching Sunday school; it’s a challenge for me, but I enjoy it.”

- Gretchen Carter Lowery, living with dementia

Call to Action

Despite the progress made for inclusivity in dementia treatment and care, there are significant challenges still facing the Black community living with dementia. We hope the stories, lessons, and ideas captured in this paper can help to spur action and call readers to become better and more informed advocates for the Black community with dementia.

Here are three things we can all do to support Black Americans living with dementia

1. Support the work of advocates to address systemic racism within healthcare systems

- Learn more about Black history to understand the marginalization, exploitation, and discrimination that has occurred throughout the healthcare system.
- Speak up when dementia resources exclude the Black community.
- Support advocacy groups who work to increase accessibility to care and education for the Black community.

"Every person should be treated equally, no matter what color. They shouldn't have to be reminded that they're Black, they shouldn't have to be reminded that they're poor, they shouldn't have to be reminded that someone else can make decisions like 'you can't have this, or you can't pay for this.'"

- *Terrie Montgomery, living with dementia*

"We have to be able to validate the things that have happened, we need to talk about it, and we need to hear apologies, if there are apologies owed. Let's get it out and then let's talk about solutions and how we can be more inclusive to the community."

- *Valene Campbell, care partner*

2. Support efforts to destigmatize and foster conversation around dementia in the Black community

- Support organizations that provide education or resources around dementia or mental health in the Black community.
- Promote the dissemination of inclusive informational material about dementia through your networks (Church, employer, schools, neighborhood, etc.).
- Find ways to support those in your community who may be impacted by dementia.
- Consider sharing your diagnosis or a loved one's diagnosis with your community.

> "Let's recognize what racism was and what still takes place, and let's deal with that. However, we can't let that stop us from seeking help for our loved ones."
>
> *- Debra Tann, care partner*

3. Improve available resources during the diagnosis and the ongoing management of dementia

- For health care providers:
  - Provide educational materials and resources at the time of diagnosis. Connect people and their families to groups that can provide support and community.
  - Provide a compassionate diagnosis and offer messages of hope and support.
- For the community
  - Share dementia resources and tools with your networks.
  - Offer support to those in your community living with dementia and their loved ones.
  - Support organizations that distribute or provide resources for the dementia community.

Resources

Organizations

AfricanAmericansAgainstAlzheimer's

AfricanAmericansAgainstAlzheimer's is the nation's first organization dedicated to building a coordinated national response to eliminate and address Alzheimer's disease (AD) among African Americans.

African-American Alzheimer's Caregiver Training and Support Acts 2

The African-American Alzheimer's Caregiver Training & Support Project (ACTS 2) provides support to African American Alzheimer's caregivers through free caregiving support sessions and telephone-based training.

Alter

The Alter Program was created in 2019 at Georgia State University to address the lack of resources and awareness around dementia in African American and faith communities. The organization works with churches to create dementia-friendly and inclusive environments. Their services are free.

Life After Dementia

A Facebook group created by Toya Algarina, a care partner of her mother living with dementia. This group of Black American care partners shares information, resources, and friendship

The African American Alzheimer's and Wellness Association

With African American's having the greatest risk for developing Alzheimer's, this organization was created to provide much needed support and education.

Vine Street Café

A welcoming virtual place for Black American individuals experiencing cognitive impairment and their care partners. Zoom meetings are at 10am ET on the second Friday of each month.

Pamphlets, guides, toolkits, videos

“Is it Alzheimer’s or Just Signs of Aging? 10 Signs Every African American Should Know”

- **Alzheimer’s Association**

This brochure outlines 10 warning signs of dementia African Americans should be aware of.

“Memory Sunday Toolkit”

- **The National Brain Health Center for African-Americans**

This toolkit is part of a campaign to raise awareness of Alzheimer’s disease and cognitive health among members of African American churches.

“Serving African American Families: Home and Community Based Services for People with Dementia and their Caregivers”

- **Alzheimer’s Association**

This toolkit offers links to local dementia services and outlines actions states can take to improve support and awareness around dementia in African American communities.

“Tackling Dementia Through Black Churches”

- **Being Patient**

This live talk is with Fayron Epps, principal investigator at the Faith Village Research Lab and founder of the Alter program.

“The Costs of Alzheimer’s and Other Dementia for African Americans”

- **UsAgainstAlzheimer’s**

This report discusses the cost and economic burden of dementia on the African American community.

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